

**Virginia Genetics Advisory Committee
Tuesday, October 4, 2005
10:00 a.m. – 12:00 Noon**

**Division of Consolidated Laboratory Services
Training Room T-23
600 North 5th Street
Richmond, VA 23219
Telephone (804) 648-4480**

MINUTES

Present: Allison Schreiber, MS-VDH/VCU; Charlie Stevenson, MS—DCLS; Jene O. Radcliffe-Shipman—VDH; Joann N. Bodurtha, MD, MPH, Chair—VCU; Kathy Orchen—VDH; Laura Duncan, MPH, RD—VCU; Lynette Bartlett, RN—VDH; Mary Ann Discenza—DMHMRSAS; Melody Persinger Yeargin—CHKD; Nancy Bullock, RN, MPH—VDH; Nancy Ford, MPH, RN—VDH; Ramona Schaeffer—VDH; Raphael Randolph—VDH; Sara Long—MOD; Virginia (“Ginny”) K. Proud, MD—CHKD; Walter Nance, MD, PhD- VEHDIP Adv Cmt.; William (“Bill”) G. Wilson, MD—UVA Health Sciences Center; Willie C. Andrews—DCLS

Absent: Arti Pandya, MD, MBA—VCU; David Suttle, MD—VDH; Gwen Smith, RN, MSN—DOE; James Pearson, DrPH, BCLD—DCLS; Joan Corder-Mabe, RNC, MS, OGNP—VDH; MS, RN—VDH; Joanne Boise, MSPH—VDH; Sharon Williams, MS, RN—VDH

Recorder: Rafael Randolph

1. Welcome: J. Bodurtha

- a. Introductions: Completed.
- b. Minutes of 3/29/05: Approved as written. Final minutes will be posted on the VDH Minutes Calendar Web site: <http://www.vdh.state.va.us/minutes/minutes.asp>.
- c. Agenda: Reviewed, no new items added.
- d. Membership List: Circulated for corrections.

2. Expanded Newborn Screening: Partnership 8/23/05 Meeting Update: N. Ford

Distributed and reviewed “Expanded Newborn Screening Services Planning Session and Follow-Up Activities,” which includes a summary of the stakeholders meeting convened on 8/23/05 by J. Boise. Post-meeting areas that will be addressed include (a) Role Definition Work Group – Nancy Bullock, (b) Education Work Group – Sharon Williams, (c) Formula and Food Supplements Work Group – Nancy Ford, (d) Confirmatory Testing – Susan Tlusty and Allison Schreiber, (e) Northern Virginia Contracting – Joanne Boise and Joan Corder-Mabe, (f) Genetic Counselors Network – Allison Schreiber and Joann Bodurtha, and (g) Nutritionists Network – Carol Carr and Sharon Williams.

3. Updates: Agencies, Organizations, Grants

a. VDH: Pediatric Screening and Genetic Services: N. Ford

Awarded 5-year CDC birth defects surveillance cooperative agreement to fund Virginia Congenital Anomalies Tracking and Prevention Improvement Project (VaCATPIP II), which began 3/1/05. Key activities: improve VaCARES case ascertainment and reporting; evaluate surveillance methodology; enhance partnerships to expand birth defects prevention; evaluate progress in birth defects prevention; and improve access of care for children identified through Virginia Congenital Anomalies Reporting and Education System (VaCARES), for example, to Care Connection for Children and Part C Early Intervention. In addition, was awarded 3-year CDC early hearing detection and intervention (EHDI) grant to fund Virginia Child Health

Information Systems Improvement Project (VaCHISIP), which began 7/1/05. Key activities: redesign the current integrated/linked Web-based tracking and surveillance system application, Virginia Infant Screening and Infant Tracking System (VISITS); implement an analytic plan for improving monitoring, screening/reporting, and follow-up processes; and link the new system, VISITS II, with other statewide child health information systems.

b. **VDH: Virginia Sickle Cell Awareness Program: J. Shipman**

Submitted request for Title V carryover funds for direct notification of parents of children with sickle cell trait. Developing plans to build on last Preconceptual Health Conference, which was conducted June 2005. Currently, program focus is on follow-up activities. Number of children currently followed in pediatric clinics: 1,097 newborns with sickle cell, which includes 47% in Tidewater area, 19% in Fairfax, 10% at UVA, and 24% in Richmond. Research suggests the Hispanic population is the 2nd highest carrier of the sickle cell trait. Pamphlets were translated into Spanish.

c. **DCLS: W. Andrews**

StarLims, which was started in 2001 specific to newborn screening, is being enhanced and expanded to include all of DCLS—it went live 10/9/25/05. DCLS working with VDH WebVision staff to develop system for ordering various tests online. Working on a feature called MyLims where physicians could login to the system and run queries.

d. **March of Dimes: S. Long**

The March of Dimes Web site, <http://www.marchofdimes.com/professionals/682.asp>, includes the continuing education module “Genetics and Your Practice,” which has been designed for health care professionals and customized for those working with the following patient types: preconception/ prenatal, infant/children, and adolescent/adult). In addition, the Web site includes online modules on “Perinatal Nursing Education.” If there is an interest, S. Long can sponsor a nursing conference to provide this training. The March of Dimes is focusing on preconception care as a follow up to the National Summit on Preconception Care, which took place on June 21-22, 2005, in Atlanta, Georgia. The U.S. Centers for Disease Control and Prevention conducted the conference, and the March of Dimes served on the planning committee. A pamphlet entitled “Are you ready for a baby?” was circulated. S. Long is providing liaison role for parents to Newborn Screening Subcommittee.

e. **Va. Council on Folic Acid: K Orchen**

Folic acid distribution project, which involved 19 VDH family planning clinics, began July 2005, Press release issued 7/25/05 resulted in 12 articles, 2 TV newscasts, and 2 radio interviews.

f. **DMHMRSAS: Part C of IDEA: Infant & Toddler Connection of Virginia: Mary Ann Discenza**

No report.

g. **Dept. of Education: G. Smith**

No report.

4. **Updates: Virginia Genetics and Metabolic Centers**

a. **Eastern Virginia Medical School: G. Proud**

Gerald J. Pepe, Ph.D., is the New Dean and Provost. A lot of new staff members. Recruiting for another genetic counselor position.

b. **University of Virginia: W. Wilson**

Staffing is stable, all genetic counselor position filled. Recruiting for another medical geneticist.

c. **Virginia Commonwealth University: J Bodurtha**

Jerome F. Strauss III, M.D., Ph.D., was appointed dean of VCU’s School of Medicine. VCU’s Partnership for People with Disabilities has received a HRSA/MCHB grant to develop a leadership-training program for genetic counselors who work with children with special health care needs. The program, SYNERGY, is a collaborative effort between the Virginia Leadership Education in Neurodevelopmental Disabilities (Va-LEND) and the Genetic Counseling Program in the VCU School of Medicine. Continue to collaborate with VDH on VaCATPIP activities.

Will apply for another March of Dimes grant. According to VaGENE phone survey, which was funded by March of Dimes, 10% of Virginia's population have had genetic services in past 5 years.

5. Subcommittees and Work Groups Reports

a. Newborn Screening Work Group: W. Andrews

Newborn screening kit fee will be increased from \$32 to \$53 effective 11/1/05 to cover costs of expanded screening, which begins 3/1/06. DCLS began to send letters to submitters regarding fee increase June 2005. DCLS and VDH recruiting for new staff. DCLS has made physical changes to lab to accommodate cystic fibrosis testing equipment, which is being procured. A work group session was held on 8/11/05 in which cut-off values for metabolic screenings were established using a 3-tiered approach: normal, abnormal, and critical. A second work group session will be convened to establish cystic fibrosis cut off values. DCLS developing a "How to Report" document. VaGAC recommended the document be reviewed by a non-expert physician. Plan: W. Andrew will coordinate with J Bodurtha. VaGAC supported DCLS recommendation to discontinue the repeat requirement if infant was on antibiotic because there is no scientific evidence to support a repeat screen. Plan: DCLS will send out official notice.

b. Parent Involvement Work Group: A. Schreiber

Will soon involve parents in reviewing new Virginia Newborn Screening Services fact sheets. VaCARES parent contact remains on hold until birth and death certificate matching methodology completed.

c. State Genetics Plan Work Group: J. Bodurtha

March of Dimes grant, if funded, would include a part-time position. Requested VaGAC volunteers for work group. New volunteers include V. Proud, N. Ford, A. Schreiber, and K. Orchen. Work group focus: education and services.

d. VDH Contractors Subcommittee: S. Williams

No report on VDH Contractors Subcommittee. L. Bartlett introduced Audrey Greene, RN, who is a new nurse in VNSS.

6. VaGAC Infrastructure, including membership: J. Bodurtha

VaGAC recommended that N. Ford send email to inactive members to inquire if they want to remain on VaGAC. Plan: N. Ford will follow up.

7. New Business: All

No new business.

8. Next Meeting: J. Bodurtha

Date: Tuesday, April 4, 2006

Time: 10 a.m. – 12 p.m.

Location: DCLS

9. Adjourn: J. Bodurtha

Meeting adjourned at 12 p.m.